

WORKSHOP 2

ADVOCATING FOR PATIENT- CENTRED RESEARCH / POLICIES

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“ A STRONG PATIENTS’ VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

Objectives

- Participants recognise the unique input patients can provide to research policies;
- Participants differentiate the different levels of actions and advocacy (local, national, European level);
- Participants reflect on the individual vs. collective contribution patients can make to research policies;
- Participants identify “enablers” and “barriers” to patients’ involvement in research policies.

Structure

- Introduction, objectives of the workshop, tour de table (5 minutes)
- Short presentation on the Lupus survey: an example of how patients can contribute to the research policy (20 minutes)
- Discussion / brainstorm

1. How can patients contribute to shaping the research agenda and funding priorities?
 1. At local level?
 2. At national level?
 3. At European level?
2. What main barriers to patient organisations face at different levels?
3. What is the role of individual patients vs. patient organisations, how are they complementary or conflicting?
4. How can patients' involvement and participation in research be structured and supported? Who should do this?

1. 3 main barriers identified
2. Main stakeholders/ partners
3. 3 ways to enable patients' contribution to shaping research priorities at each level
4. 3 “actions” for individual patients and patient organisations to support patient organisations' input in research policies
5. Others?